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Impact of hemoglobinopathies upon behaviors of adolescents

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Abstract---Background: Hemoglobinopathies are the most common life threatening, monogenic disorders in the world. The most common causes of hemoglobinopathies are sickle cell disease and thalassemia. Objectives: The purpose of this study is to investigate Impact of Hemoglobinopathies upon Behaviors of Adolescents in Karbala City/ Iraq. Methods: The cross-sectional study with quantitative approach was carried out on 200 participants who were attending hereditary blood disease center in Karbala teaching hospital for children. The questionnaire's dependability was established through a pilot study, and it was subsequently presented to experts for validation. The information was collected through the use of interview techniques and evaluated using descriptive and inferential statistical analysis. Results: Findings demonstrated that the (49%) of Hemoglobinopathies adolescents were poor health behavior, no-significant differences in health behavior with regards hemoglobinopathies adolescents gender, and Findings demonstrated there were significant differences health behavior with regards disease related relative among hemoglobinopathies adolescents ($p < 0.05$). Conclusion: Age, gender, and disease relative have been influencing on quality of life and health behaviors of adolescent with hemoglobinopathies

Keywords---impact, adolescent, hemoglobinopathies.

Introduction

Thalassemia is caused by a decreased or absence of a hemoglobin (Hb) tetramer beta-globin chain synthesis consisting of two alpha and (2) beta-globin chains

"alpha2beta2". The clinical occurrence of beta-thalassemia is associated with the difference between chains of alpha globines and non-alpha globins ⁽¹⁾.

Hemoglobinopathy is a condition in which abnormal hemoglobin is present. A large percentage of the newborn's hemoglobin is fetal hemoglobin (Hgb F). Hgb F can exchange oxygen molecules at lower oxygen tensions compared to adult hemoglobin. Over the first several months of life, Hgb F levels fall as it is replaced with Hgb A (adult hemoglobin). The healthy older infant then displays Hgb AA. In hemoglobinopathies, this normal hemoglobin configuration is disturbed. Causes of hemoglobinopathies are genetic and include sickle cell anemia, hemoglobin SC disease, alpha-thalassemia, and beta thalassemia ⁽²⁾.

For the adolescent with an infirmity or chronic illness, and for his family, there are exists specific problems in addition to those encountered by a healthy adolescent. The painful realization of social, professional and relational barriers is reactivated. The feeling of failure and helplessness, somatization, impairment of self-esteem, and anger at being the victim of the unfairness of destiny, represent a supplementary affective burden for the adolescent and his family ⁽³⁾.

The hemoglobinopathies creates a burden not only on health system but also on the affected families, and children, which become vulnerable to emotional, social, psychological and behavioral problems ⁽⁴⁾. Patients with β -TM are suffering from disease chronicity including frequent hospitalization, blood dependence, continuous treatment with ICT; physical health limitations as growth retardation, poor physical appearance, and delayed puberty, in addition to disease complications ⁽⁵⁾.

Methods

Cross-sectional descriptive study design is conducted in Karbala City among adolescent with hemoglobinopathies to investigate Impact of Hemoglobinopathies upon behaviors of Adolescents. By a non-probability (purposive) samples of 200 subjects who attending hereditary blood disease center.

Instruments

The instruments underlying the study phenomenon deals with the following:

Socio-demographic characteristics

- A. A-This include age, gender, marital status, occupation and income.
This section includes data about the child's age, gender, class, residency, the child's birth order in the family...
- B. B- Parent's demographic data
This part concerned with the parent's demographic data; parent's educational level, occupation, family income, family number, and residence ...)

Adolescent behaviors Questionnaire

Adolescent Behavior Checklist (ABC) . The ABC is designed to assess behavior and associated features in adolescents between the ages of 11 and 17 years. Adolescent respondents are instructed to rate each item on a 4- point Likert scale with respect to the degree that he or she has experienced that problem in the past six months: "not at all" (0), "just a little" (1), "pretty much" (2), and "very much" (3). Its initial psychometric properties are satisfactory. Seven scores were calculated: total ABC score and six factor scores (Adams et al., 1997).

Validity

Validity was given to a panel of 15 arbitrators, including nursing science experts. Arbitrators were asked to offer their opinions and suggestions on each of the study questionnaire's components in terms of language appropriateness, association with the dimension of study variables to which it was assigned, and suitability for the study population. These experts were asked to review the questionnaire for content clarity, relevancy and adequacy; their responses indicated that minor changes should be done to few items. Such changes were made according to their suggestions and valuable comments.

Reliability

Reliability was known as the scope by which a consistently measures of concepts throughout instrument (Burns& Grove 2010). The pilot research was carried out to determine the reliability of the research tool. Cronbach's Alpha was performed to measure the reliability of the present study instrument by the use of the Statistical Package for Social Science Program (IBM SPSS) version 25.0. The reliability of instrument was ($r = 0.862$) . The result of the Cronbach's Alpha reliability of the study tool was statistically high, indicate that the study tool was reliable and has equal measurability.

Statistical Analysis Approach

The SPSS version 20.0 software application was used to conduct statistical analysis (SPSS). The information was evenly spread.

Results

Table 1: Overall Health Behaviour among Hemoglobinopathies Adolescent

| | Freq. | % | <i>M ± SD</i> |
|------------------------------|-------|-------|-------------------|
| Poor (<i>M=47-94</i>) | 98 | 49.0 | <i>94.0±28.74</i> |
| Moderate (<i>M=95-141</i>) | 82 | 41.0 | |
| Good (<i>M=142-188</i>) | 20 | 10.0 | |
| <i>Total</i> | 200 | 100.0 | |

M: Mean for total score, SD=Standard Deviation for total score

Findings demonstrated that the (49%) of Hemoglobinopathies adolescents were poor health behaviour with average of $M \pm SD=94.0 \pm 28.74$.

Table 2: Significant Differences in Health Behaviour with regard Adolescents Age ($n=200$)

| Age | Source of variance | Sum of Squares | d.f | Mean Square | F | $p \leq 0.05$ |
|-----------------|--------------------|----------------|-----|-------------|------|---------------|
| Health Behavior | Between Groups | .540 | 2 | .270 | .734 | .481 |
| | Within Groups | 72.494 | 197 | .368 | | |
| | Total | 73.033 | 199 | | | |

d.f: Degree of freedom, F: F-statistic

Findings demonstrated there were no significant differences in health behaviour with regards hemoglobinopathies adolescents age ($p > 0.05$).

Table 3: Significant Differences in Health Behaviour with regard Adolescents Gender ($n=200$)

| Variables | Gender | Mean | SD | t-value | d.f | $p \leq 0.05$ |
|------------------|--------|-------|--------|---------|-----|---------------|
| Health behaviour | Male | 2.069 | .61879 | 1.469 | 198 | .143 |
| | Female | 1.943 | .59149 | | | |

SD: Standard deviation, t: t-test, d.f: Degree of freedom, Sig: Significance, p: Probability value

Findings demonstrated there were no-significant differences in health behaviour with regards hemoglobinopathies adolescents gender ($p > 0.05$).

Table 4: Significant Differences in Health Behaviour with regard Disease Related Relives ($n=200$)

| Disease related relives | Source of variance | Sum of Squares | d.f | Mean Square | F | $p \leq 0.05$ |
|-------------------------|--------------------|----------------|-----|-------------|-------|---------------|
| Health Behavior | Between Groups | 3.781 | 3 | 1.260 | 3.567 | .015 |
| | Within Groups | 69.252 | 196 | .353 | | |
| | Total | 73.033 | 199 | | | |

d.f: Degree of freedom, F: F-statistic

Findings demonstrated there were significant differences health behaviour with regards disease related relative among hemoglobinopathies adolescents ($p < 0.05$).

Discussion

Table 1: Overall Health Behaviour among Hemoglobinopathies Adolescent

Findings demonstrated that the (49%) of Hemoglobinopathies adolescents were poor health behaviour with average of $M \pm SD=94.0 \pm 28.74$. This finding in parallel with ⁽⁶⁾ who carried out a cross-sectional descriptive study was conducted study ,

and reported that Due to distress from both the illness itself and the need for iron chelation, thalassemia subjects frequently display maladaptive coping strategies and high levels of anxiety with psychosocial dysfunction . The probability of behavioral abnormality in children with TM has been estimated to be 1.6-fold higher than that in healthy children . In another study that carried out by (7) to assess the behavioral problems in multi-transfused thalassemia children and psychosocial factors affecting them , who their results indicated that the CBCL total scores were high in 32% patients, indicating the presence of behavioral problems. Higher CBCL scores were found in children of older age group, those with poor school performance.

Table 2: Significant Differences in Health Behaviour with regard Adolescents Age (n=200)

Findings demonstrated there were no significant differences in health behaviour with regards hemoglobinopathies adolescents age ($p>0.05$). This findings in the same line with (8) who conducted a study about The Effects of Patients' and Care-Givers' Knowledge, Attitude, & Practice (KAP) on Quality of Life Among Thalassemia Major Patients' in Damascus-Syrian Arab , and reported that there were differences between males and females regarding to the four domains of quality of life, and it were higher in males than females in psychological and environmental domains, while it was statistically significant in social relations in females than males (71.2±22.2 compared with 66.1±26.2) ($p=0.04$)

This may have been because the studied children got used to the presence of the chronic disease while their ages advanced.

Table 3: Significant Differences in Health Behaviour with regard Adolescents Gender (n=200)

Findings demonstrated there were no-significant differences in health behaviour with regards hemoglobinopathies adolescents gender ($p>0.05$). This findings incongruent with (9) who carried out a study to determine the strongest predictor of QOL, compare QOL between the adolescents with beta-type major and their peers in Abadan city. and illustrated that no significant relationship was found between quality of life and gender. In the same context, the finding of current study consistent with (8) who reported that, The findings show there were differences between males and females regarding to the four domains of quality of life, and it were higher in males than females in psychological and environmental domains, while it was statistically significant in social relations in females than males (71.2±22.2 compared with 66.1±26.2) ($p=0.04$), the overall quality of life was higher in females than males but without statistically significant The difference may be due to different measurement tools, race, age groups, etc. In each region, this issue should be considered specifically according to which clinical decisions should be made.

Table 4: Significant Differences in Health Behavior with regard Disease Related Relives (n=200)

Findings demonstrated there were significant differences in quality of life and health behavior with regards disease related relative among hemoglobinopathies

adolescents ($p < 0.05$). This findings congruent with ⁽¹⁰⁾ who reported that At last the Family history has significant association with all quality of life domain.

Conclusions

Less than half of adolescent have poor health behavior , and Age , gender, and disease relative have been influencing on quality of life and health behaviors of adolescent with hemoglobinopathies.

Recommendation

1. Health educational programs about thalassemia disease and nursing care are essential for children with beta thalassemia and their mothers.
2. Beta thalassemia major education should be maintained through a multidisciplinary approach over a prolonged outpatient, inpatient, and community education service plan for beta thalassemia children and their mothers.
3. Further studies with larger sample size or multicenter studies with longer period of follow-up.

Financial disclosure: There is no financial disclosure.

Conflict of interest: None to declare.

Ethical Clearance

Official approval was received from the Karbala health directorate and directed to the center for training and development in the Karbala health directorate, the primary approval took to facilitate the research mission and collect the data from hereditary blood disease center in Karbala teaching hospital for children, and after the meeting of research commitment of training and development center the final decision of Approval to conduct research had obtained

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